

Airing Pain Programme 44: Pain management at both extremes of life

Pain experienced by the very young and very old, and the similar issues arising when dealing with these very different types of patient.

This edition has been funded by the Big Lottery Fund's 'Awards for All' programme in Northern Ireland.

*In this edition of **Airing Pain**, Paul Evans speaks to experts from Belfast and London about the similarities, differences and challenges in treating pain in infants and the elderly.*

Maria Fitzgerald, Professor of Developmental Neurobiology at University College London, mentions the outdated theory that babies do not experience pain and how this misconception has been disproved. She raises the issue of communication, perhaps the biggest problem with babies and the elderly (particularly those with dementia) – if they cannot communicate about their pain effectively, their pain often cannot be adequately addressed. She also discusses the scientific research she and her team are carrying out as well as the importance of treating pain at an early age.

Paul speaks to Dr Pamela Bell, Chair of the Pain Alliance of Northern Ireland and former Lead Clinician for Pain Services at the Belfast Trust. She discusses how pain treatments work for infants and the consequences of not managing pain during the early stages of their development.

Peter Passmore, Professor of Aging and Geriatric Medicine at Queen's University Belfast, talks to us about the large number of dementia patients who are thought to live with pain and the need for medical staff and carers to be able to recognise changes in patients' behaviour and therefore become more able to address their pain.

Paul Evans: Hello, I'm Paul Evans and welcome to **Airing Pain**, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain. This edition has been funded by the Big Lottery Fund's 'Awards for All' programme in Northern Ireland.

Maria Fitzgerald: It is estimated that some preterm infants will have 20-25 such procedures a day in their period of intensive care.

Peter Passmore: The people who seem to do badly as far as pain is concerned are the very elderly, so over 85: it would be men, racial minorities and those with memory problems.

Evans: From cradle to grave: the extremes of life when, for some of us, we will be or have been at our most vulnerable. How is pain assessed and managed in those two groups and what common issues do they share for the healthcare professionals?

Dr Pamela Bell is Chair of the Pain Alliance of Northern Ireland and a former Lead Clinician for Pain Services at the Belfast Health and Social Care Trust. She's an anaesthetist and some years ago she, and some of her colleagues, set up a Masters course at Queen's University Belfast in the science and practice of pain for healthcare professionals. One of the modules they teach covers pain for those vulnerable groups at the extremes of life.

Pamela Bell: When one tries to assess pain for most people, it's a question of asking some questions and receiving answers. For those who are very young and preverbal, the neonate and the infant and very young children, that is not a very reasonable way to proceed. Similarly, those who have dementia may not be in a position to communicate their pain in the way that is easily assessed using commonly used pain tools, and as such we felt that there was perhaps a discrimination against those at the end or the beginning of life, in that their pain was not being addressed in the way that it would be were they able to communicate their pain in the usual way.

Evans: So basically, I as a middle-aged man, and for the last fifty-odd years, I have been able to tell you about my pain. Before that, I would've had problems?

Bell: Before that you would've had a lot of problems, and in fact there was a belief that, for example, newborn infants did not suffer pain in the way that we do. Infants of course cry: crying per se is not necessarily an indication of pain – it could be hunger, or being too hot or too cold. So, healthcare professionals and doctors must take some responsibility for this and anaesthetists, I might add, were often very reluctant to use painkillers, particularly strong painkillers when infants had surgery.

This was really a state of affairs that existed even as late as the 1970s to 1980s and, in fact, one of the things I read to my students when they first come on the course is a little paragraph from an American book, in fact, where a mother writes about her experience of having an infant who needed to have heart surgery and speaking to the anaesthetist

afterwards about his distress and why he hadn't had more pain relief. And the anaesthetist said 'Well, I don't really think that children this young have much by way of pain, therefore they don't get much by way of pain relief.'

We now know from research that this is far from the truth, and that the consequences of pain in very young infants can be *more* than for similar operations in older children because the neonates have a *very* immature nervous system and respond *more* dramatically to pain than older children and adults will.

Evans: Pamela Bell. Now, I want to return to that discredited thought that babies do not experience pain. Neuroscientist Maria Fitzgerald is Professor of Developmental Neurobiology at University College London. Her main research interest is in how the central nervous system develops in infants and children.

Fitzgerald: It was considered that since we have no overt memory or recall of events that take place when we're young, and among that we do not recall any tissue-damaging or noxious or painful stimulation, that really meant that it wasn't a concern that if a baby did experience pain they certainly didn't remember it so that maybe didn't matter very much. But the early 1980s brought a series of really pioneering studies carried out by scientists, mainly in Canada, actually, but also in the UK and elsewhere, that showed that there were a range of behaviours in very, very young infants that were specific to what we would describe as a 'painful stimulus', and it became clear that really even premature infants, and by that I mean infants at the earliest viable age: is I suppose 24-25 weeks gestation, so from that age onwards infants were clearly able to show a set of behaviours which were special to a painful stimulus.

And that really changed the whole climate if you like, the recognition that this could not be ignored and because we don't remember something doesn't mean that it isn't important that it's taking place. Importantly also, it could be that those painful events may be altering the normal development of the nervous system and that's a very important aspect of thinking about this.

Evans: So, talking about premature babies, it's in that period in the special care units that they get poked and prodded, tubes pushed down them, needles, blood tests, a lot is happening?

Fitzgerald: Exactly, and in fact a number of papers have very carefully monitored the number of interventions that these tiny premature infants get. If you simply ask medical staff

'Which of those interventions do *you* consider painful? Would *you* feel pain if it was carried out on yourself?' It is estimated that some preterm infants will have 20-25 such procedures a *day* in their period of intensive care. Now I want to emphasise, I'm sure everyone will realise this isn't being done callously or deliberately in any way. This is as the result of the clinical care that the babies require in order to stay alive and certainly to develop normally.

The difficulty is, we don't understand enough about this pain and we also don't understand enough about how to alleviate it, how to treat it in a way that is safe for a very young baby. So for instance, filling the baby up with morphine may not be a good idea, it may affect their respiration, it may affect other aspects of their physiology so it's a question of the medical and scientific community facing up to this, learning how to measure it, and thinking of good ways to try and alleviate the pain.

Evans: So what research do you do and what does it show?

Fitzgerald: OK, so there are two strands to my research. In the laboratory we use animal models of infant pain and also we look at individual neurons and circuits and we study the development of the pain circuits, but we also have a whole branch of research where we collaborate with neonatologists and we try and measure in these preterm infants, what it is that's actually going on in their brain when they are undergoing what we would consider 'painful procedures' and these procedures have to be done, they're done for clinical reasons and we would never ever stimulate a baby just experimentally.

So we tap in to the existing clinical procedures and we measure activity in the brain and we measure it in two ways: one is by using a technique called 'EEG' or electroencephalography which many people would have come across already where electrodes are put on the scalp, they don't hurt, they're not invasive, they're just placed on the scalp and the activity that's going on in the brain underlying the scalp can be monitored – that's one method. And the other method is the 'hemodynamic method' where infrared optodes are placed, again, just on the scalp, they're not invasive in any way, and they measure the blood flow and the oxygenation of blood under the optodes, but that's the blood in the brain that they're measuring. So these are two techniques that can be used at the cot side on the ward and they can directly measure brain activity.

So I mentioned earlier that a lot of work has been done on the behaviour of these babies but this is a more direct measure of what activity is going on in the brain as a response to, let's say, for example, a needle puncturing the skin or a lance, such as the kind of lance that diabetics have to use, is a procedure that is often used on very young babies because they

need to have blood samples taken really often and their blood gases measured. So this is a routine, painful procedure that we can tap into, if you like, and see what kind of activity is occurring in the brain.

And we've been able to show that even the very youngest infant shows a very strong activity in the neurons in their brain, very immature brains, but very strong activity to every noxious stimulus, but the pattern of that activity changes as they grow up, which is not surprising, so the research that we do is to try and unravel those changes to understand them better and, hopefully perhaps, to be able to use those as a way to monitor their pain and investigate methods of alleviating that pain.

Evans: I can't remember having blood tests taken from me when I was a baby, we can't remember it, but is it being imprinted in the brain that will affect us later?

Fitzgerald: That's a very good question. Neuroscientists think of memory in two ways: there's the memory that is normally used in general conversation, and actually what that means is 'active recall' that you can actively recall an event, but you're quite right: there's another type of memory which you call 'imprinting' which is a good way of thinking about it, which is that changes have been made in the nervous system which do not involve active recall but which will lead to altered patterns of activity in future life.

In animal models, because we don't know it happens in man, but in animal models a small noxious stimulation in the early part of life does have an imprinting effect on the nervous system such that if when the animal grows up and has the same stimulus again, it reacts in a more exaggerated way than the animal that's never had it before so it's as if a 'pain history', if you like, from a critical stage of development stays with you in the nervous system. So that is a form of memory even if you can't recall it: it has changed you and it stays with you.

Evans: But are you saying that what happens at that early stage in life can affect things like neuropathic pain?

Fitzgerald: This we don't know and I think it's a very interesting question. Is it possible that your developmental history, 'pain history' if you like, might actually influence your propensity to develop chronic pain? And that is a big research question that we simply don't know the answer to, so I wouldn't like to speculate on that but it's a reasonable hypothesis. It wouldn't be the only factor: there'd be genetic factors and many other factors, but it's possible that your early life pain experience does make you possibly more *or less* vulnerable to the onset of chronic pain, but there isn't strong evidence either way.

Evans: That's Maria Fitzgerald, Professor of Developmental Neurobiology at University College London.

Now 56 years ago I had an operation for a condition called pyloric stenosis. Today it's done by keyhole surgery but the scar down my abdomen is evidence of a procedure that was considerably more invasive. So how would the doctors have judged my pain? Anaesthetist Pamela Bell.

Bell: I think they would have listened to your crying and I think your parents would have noted how your behaviour changed, for example some children who have just had surgery on their tummies don't move because it's just too painful and so therefore they lie very still.

And if your mum and dad were used to you kicking your arms and legs they would notice a difference and, in fact, some of these changes which weren't always interpreted as pain made their way into the form of assessment of pain in infants and children, so while there are many, many different pain assessment tools out there, those that are used after surgery look at things such as crying, such as facial expressions, such as screwing up the eyes, or the shape of the mouth, the general movement of the body: whether the legs are kicking or not and these are scored by the healthcare professionals – the nurses, usually – looking after the infant and, as a result, a determination is made of the likely level of pain that that child is experiencing and the best of these scales have been rigorously tested in a number of institutions, and show that when pain relief is then given, the score falls.

In other words, the behaviours, the crying, the grimacing alter in the direction of a lower score. So we think that many of these scores have been well validated, so now if it were to happen that you had an infant undergoing similar surgery you would work with the nurses to assess that pain.

Evans: Because most mothers and fathers can recognise the different cries of their baby as feeding, tiredness, wet nappy, pain and so should work with the anaesthetists.

Bell: Oh absolutely, absolutely. And the more experienced the parent, the easier that will be. *[Laughs]* I know that first-time mums often find it difficult to know what's happening in terms of the cry at first and it is a learning process, so as they observe their infants they learn for themselves to distinguish the type of cry that is likely to indicate pain in their infant.

Evans: Can young children like that develop chronic pain conditions?

Bell: What has been shown by some studies, for example of circumcision in infancy, is that if pain is not well managed at the time of operation, in later life the child can go on to experience more pain, with a given procedure, than they would have, had their pain been well managed at the time. And there are other studies looking at vaccination pain and so on and so forth. So there is some evidence out there that failing to care for pain in young infants has a long-term impact.

Evans: Anaesthetist, Dr Pamela Bell. I'll just remind you that whilst we in Pain Concern believe the information and opinions on *Airing Pain* are accurate and sound, based on the best judgements available, you should always consult *your* health professional on any matter relating to *your* health and wellbeing. He or she is the only person who *knows* you and your circumstances and therefore the appropriate action to take on *your* behalf.

Now this edition of *Airing Pain* is looking at pain management of those at the extremes of life. Moving from those at the start of life's journey to those approaching the end, similar issues are faced by those trying to assess and therefore manage a patient's pain. Professor Peter Passmore is professor of aging and geriatric medicine at Queen's University Belfast. His main clinical and research interest is dementia.

Passmore: It's fascinating to hear how Pamela deals with those very, very young children. There are difficulties eliciting from them, whether they're in pain or not, how bad it is or what might be going on and you put it in [the] context of somebody that I see, particularly with dementia where if they seem to be *not right* shall we say, for whatever reason, one of the causes for that can be pain and I think it's very important to be aware of that and to detect it and try and deal with it if you think that's what the problem is. The issues around management in children and in very old people are slightly similar because when it comes to management, you like to be able to refer to an evidence base and for older people, in general, for many treatments we don't have a decent evidence base with good clinical trials; that's particularly the case for pain. And the same can be said for the pain and dementia issue.

Evans: I suppose a major part of that are for people in nursing homes with dementia and the staff looking after them?

Passmore: Aye, that's absolutely right. I mean, I think it's about having an awareness that pain could be a problem. It involves a number of people, and you're absolutely right, it does depend on the location that older people find themselves, so it applies to people at home, and again if they have cognitive impairment or memory difficulties or dementia, it might be

the carer that you're relying on that knows them and who one would look to to get an indication of what might be going on. But equally well, there are large, large, large numbers of older people now in the independent sector in nursing homes and many of them have dementia, but many haven't been diagnosed with dementia and we know for a fact that the statistics would seem to indicate that perhaps in those people, two-fifths to a half might be in pain at any one time and about two-fifths are on any form of treatment.

So from a medical perspective we can treat the situation if it's brought to our attention and this is where you've mentioned the staff in the nursing homes; to have them educated and up-skilled in some way about this awareness thing and also maybe how to assess pain a little so they can bring it to medical attention in case medication is required, but also it could be if it's not medication, it may be that the physiotherapist might be important or the occupational therapist, so it's a multi-disciplinary approach and it doesn't always mean drugs; it often does mean medication, but it doesn't always mean that. But the key thing at the outset would be that there's this awareness detection thing needs to be there, and I think the problem is that's very variable.

Evans: If I were looking after one of my parents, I've known my parents for 56 years, I would recognise different things from them, as Pamela was saying with babies, they would recognise different noises, different movements, things like this, that and the other. My father was in a care home and he'd been looked after by various people coming in who don't know the real person.

Passmore: You're absolutely right when you say it's about knowing people. I think if you take the person with dementia for example, and the pain assessment guidelines that are there, what is key is that we should look at the patient first and attempt to illicit from them whether they're in pain or not, and certainly with people with even more advanced dementia can often indicate whether that is or isn't likely to be the case but if you're not able to get this, if communication is a problem, then you're moving to a more observation sort of mode and you're absolutely right when you say it's the change in the person that's key. It's the change in some sort of behaviour, some of which are easier to think they'd be associated with pain, perhaps the fidgeting, or people being noisy or shouting. But equally well, people can go from loud to quiet and this can be a feature of old people.

There can be atypical responses to pain and I think this is where the knowing of the individual is probably fairly critical and I think, for example, in the home situation and the carers are there, it would be foolish to ignore if a carer comes along and says, 'I think they're

in pain' and it is often the case that the pain doesn't suddenly arise; these are chronic painful conditions so we know probably in quite a percentage of people that there is a pain-causing condition there in the background. Therefore, if there is a change I think what one normally looks at, what is the list of complaints here or what are the medical complaints and if there's a pain-causing condition it seems a bit daft to ignore what's staring you in the face, really.

Evans: Is it all too easy to put somebody down as a 'grumpy old man'? They put me down as a grumpy irascible old man when in actual fact I'm a mild-mannered man who was turned grumpy, but they can't see that?

Passmore: [*Laughs*] I think that's right. It comes back to knowing about the patient. I think the efforts aimed at trying to deal with say, people who have behaviour abnormalities or people that are behaving irrationally, for want of a better word, that's also where it comes to knowing about the patient so you'd like to think if you were somewhere, people might have some sort of a dossier about you: what are your likes/dislikes; what were you like, and then if it comes over clearly that here is someone who has been mild-mannered all the way along and then there is an overt change. Again, that should set you to thinking. It's interesting – the people who seem, from an American study a few years ago, to do badly as far as pain is concerned is the very elderly, so over 85 – it would be men, as you mentioned about being a grumpy old man, racial minorities and those with memory problems. I think you ought to be in a situation where you are looking out for those as the odds seemed to be stacked against people to start with.

You may well be a grumpy old man but the number of times people say to you, 'Look, I'm in pain again but sure you know, it goes with the territory. It's part and parcel of where I'm at age wise and what should I expect.' Chronic pain – that's often what we're talking about, which will flare up but chronic pain in the background, in the older people there's such an influence on things like mood, things like sleep, things like wanting to get up and walk around and do the things you normally do or be able to get yourself dressed and that sort of thing. The actual pain itself has an impact way beyond, so in terms of when you're trying to deal with it, in dealing with the pain you're also hoping to have an impact (and some studies have shown this) on peoples sleep, peoples function, peoples mood and you can see when you've had an effective pain approach. When it works, it does make a huge difference – people right across those facets, not just easing the pain but it's also the sequely of that pain. I think it's much more profound in older people than in younger people.

Evans: You've been heavily involved in educating nursing home staff in how to recognise pain in people. What're your conclusions there? What can you tell?

Passmore: They do seem very keen to want to learn. If you run a study day for nursing home staff, if you've got so many spaces, you'll probably have to turn people away and I think they really, really, really appreciate that and let's face it, they have their continual professional development to do as well as the rest of it. I'm just not sure how well it's normally catered for, so you welcome their enthusiasm. They are busy people so it's maybe working with them to try for them and come up with some sort of solution in terms of a more valid way of assessing people for pain and one that can be done fairly quick and fairly practical. You know, it's not detracting from their working day because they're very, very, very busy people as we know, so I think it needs to be some sort of scale that is quick and easy to apply and that does have some meaning and then if it flags up some possibility of pain, further assessment would happen.

If one intervenes, it would be nice to go back and look at the same thing and see that it's improved. You know, you may get a subjective view - *the patients not doing this or not doing that, or they're sleeping better so we think we've done it* – if there is a pain assessment situation there and it's possible to re-do it or re-apply it after you've gone with any intervention then I think that's good. So I think those are the general messages to try and get over and point out of course that, they are dealing a lot with dementia and these people don't have the communication so it's very important to treat them in a special way to try and get the information from them. Those would be the sort of areas or principles you would try to get across.

Evans: Peter Passmore, professor of aging and geriatric medicine at Queen's University Belfast.

Don't forget that you can download all the previous editions of ***Airing Pain*** or obtain CD copies direct from Pain Concern. If you'd like to put a question to Pain Concern's panel of experts or just make a comment about these programmes, then please do so via our blog, message board, e-mail, Facebook, Twitter or pen and paper. All the contact details are at our website which is www.painconcern.org.uk.

To end this edition of ***Airing Pain***, I asked anaesthetist Dr Pamela Bell for her advice to a parent whose child has had or is facing the prospect of surgery.

Bell: Talk to the doctors and nurses who are going to be looking after the child. Ask them what tools they use to assess pain and ask how you can help in the process of monitoring your child after surgery and helping to highlight how you feel your child's pain is. You will have noticed with your infant that their behaviour changes when they are in pain and if you can reflect that to the healthcare professionals looking after the child, then you will be well on your way to ensuring that the pain is well assessed and therefore well treated.

Evans: And advice to a health professional: listen to Mum and Dad?

Bell: Absolutely. Absolutely. They will have monitored their child's behaviour over time and since you can't ask the infant how their pain score is, utilise the parent's experience as part of your assessment tool when you're dealing with this child after surgery.

Contributors

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